

Shaping the Future of Caregiving Independent Aging Agenda Event Report to the White House Conference on Aging

The Central Ohio Area Agency on Aging conducted an Independent Aging Agenda Event on July 7, 2005 in Columbus, Ohio. The event was attended by 62 participants, including members of the private sector, faith-based communities, local universities, home care service providers, caregivers, Area Agency on Aging Staff, and legislative aides from Congressional offices. The key note speaker was the health and human services committee chair for Columbus City Council.

Below is a summary of the key issues identified and priority areas:

Priority Issue #1: Need for Awareness and Education

There was an overwhelming theme at this forum that education and awareness raising regarding the process and needs of aging, aging services, caregiver support, planning for later life, and navigating the health care and home care systems is desperately needed. This education is needed for the general public, physicians, nurses, faith-based individuals, businesses, and young children. The needs of caregivers cannot be fully understood or addressed if there is not a public recognition of the importance and complexity of this issues.

Barriers:

Barriers Identified to this area include:

- Unwillingness of the general population to plan for or think about aging, or the aging of their parents and family members
- Lack of money to do the sustained level of public awareness campaigns and education that would be necessary to create a culture shift
- Creating the public consciousness that caregiving will affect each of us, and that aging is not taboo; this includes changing the image of older adults in the media

Proposed Solutions:

- Dramatically increase funding for the National Family Caregiver Support Program, so that dollars are available for media campaigns and education on a sustained basis.
- Create partnerships between universities, businesses, AAA's, as well as with the faith-based communities to increase our ability to reach caregivers where they work, live, and learn.
- Develop and mandate curriculum in primary education regarding aging and the issue of caregiving.

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Priority Issue # 2: Health Care System Improvements

The failures of our current health care system were also heavily identified. This issues included a very complex, hard to navigate health care system, complicated by new Medicare laws under the Medicare Modernization Act. It was also felt that the medical world views individuals as “old people” with little value, and leaves the caregiver in a difficult advocacy position in the hospital, doctor’s office, or the emergency room. In addition, discharge planners no longer do “true” discharge planning. They give the caregiver a phone number to contact upon discharge, and the caregiver is left feeling helpless, with a much sicker individual than they are prepared to care for. Hospitals discharge patients long before they are well, and the responsibility falls to the caregiver to provide medical care. This led to a discussion regarding the fact that HMO’s are making the decisions regarding length of stay and treatment, not the physician.

Barriers:

The barriers to this issue are many and incredibly difficult to overcome.

- Entire system restructuring of health care system will take years to accomplish
- There is a great deal of political resistance to making sweeping changes in the health care system
- Lack of dollars to accomplish change

Proposed Solutions:

- Treat all patients holistically, and have a team approach to health care involving the physician, the nurse, the social worker, the patient, and other healthcare providers.
- Explore the psycho-social issues of older adults and caregivers in the health care environment.
- Give physicians the ability to decision-make regarding patient care back.
- Simplify Medicare Part D so that it is understandable for consumers and caregivers.
- Negotiate the costs of prescription drugs.
- Develop Universal Health Care
- Put a social worker in every physician/healthcare provider’s office
- Clarify and simplify HIPAA so that caregivers can have access to health care information
- Simplify the billing process for health care so that the amount of paper generated decreases significantly

Priority Issue #3: Financial Concerns

The next area of priority concerned financial needs of caregivers. This issue included a wide range of areas. In particular, the lack of support and financial assistance to those who fall outside the needs-based programs, but do not have the funds to private pay for care. In addition, the Medicaid laws in Ohio are extremely restrictive, and there was consensus that the asset limit was problematic, and estate recovery was often times unfair. The fact that Medicare only pays for home health care for a very brief period of time was an issue. It often leaves families without help when it is still very much needed. Many caregivers felt unprepared for the financial issues that arose with their loved one, and were significantly impacted financially by this. Finally, there is currently no financial assistance for Assisted Living in Ohio, which often is the best housing option for many older adults, but it is not accessible due to cost.

Barriers:

- The primary barrier to achieving change in this area is funding. This must become a priority for members in Congress and the White House.
- Another barrier is the controversy over Estate Recovery, its role, and whether it is an equitable policy.

Proposed Solutions:

- Provide tax incentives to caregivers for providing care to their loved one
- Create a national or statewide service system that allows all persons to receive help regardless of financial situation (sliding fee scale)
- Allow the family member to be hired to provide care so that they receive a source of income
- Build financial planning into all businesses, making it a requirement when employees hit a certain age or length of service
- Create an estate recovery system that does not encourage people to hide assets
- Allow for unique circumstances with the estate recovery policy
- Change spousal impoverishment laws to be more lenient to the family
- Work with the private sector to encourage a “caregiver” plan, allow for the cost of caregiving to the employee.

Priority Issue #4: Access to Services

The continued need for a clear, easy to access service system was strongly voiced. Often times, aging and caregiver services vary from county to county, region to region, and state to state. It is not clear where to call, who is eligible, and what to even ask for. Often times, caregivers experience the frustrating event of calling one after another agency, being passed on to yet another number. Service areas, financial eligibility, even the names of services are confusing to the caregiver. In addition, transitioning between hospital, home, and nursing home can be extremely overwhelming.

Barriers:

The current barriers that exist to changing this issue include:

- Fragmented systems that exist and cross over, such as home health, hospitals, hospice services, area agencies on aging, mental health, human services, MR/DD.
- Communication issues and territory issues between systems; where does ultimate responsibility and accountability lie?
- Need to access services for caregivers often occurs during a crisis situation, increasing the stress on a caregiver when information is hard to collect, or contradictory

Proposed Solutions:

- Create a system of navigation for caregivers and older adults with well defined roles and responsibilities. This system should be created, implemented, and managed by Area Agencies on Aging, as they are the natural fit.
- This system should work to enhance control at the local level, to avoid duplication of services.
- Additional funding for the National Family Caregiver Support Program to provide better quality access to services.
- Create a system that allows the “money to follow the person” so that as one’s needs change, caregivers have better access to all types of services and housing options.